

Testimony of Shelagh McClure in Support of HB 5534, An Act Concerning the Provision of Services to Individuals with Intellectual Disabilities

My name is Shelagh McClure from West Hartford. I am submitting this testimony in support of HB 5534. My son is 23 and has Down Syndrome. I am concerned that, under the current system of providing services for individuals with intellectual disabilities, there will be inadequate resources to support his needs.

It should be the goal of this legislature to fully provide for the needs of individuals with intellectual disabilities. Those individuals who spoke at the recent Family Hearing Day organized by the ARC of Connecticut, told heartbreaking stories of unmet needs and families under extreme stress. This state should not be content to accept a system that fails so many people it is supposed to help. HB 5534 would require the Commissioner to do a full assessment of the needs and the cost to provide all needed services for all individuals eligible for DDS services. Whether such services could be provided immediately, or must be provided according to a longer term plan, the importance of having a definitive plan, with benchmarks and timetables for implementation cannot be overstated.

My support of HB 5534 is driven largely by my concern about the DDS system for providing residential services and supports. Connecticut is saddled with a legacy system of state-operated institutions --Southbury Training School and the 5 Regional Centers--which continue to house over 500 individuals with intellectual disabilities, at a cost of approximately \$400,000 per person per year. This cost is three times the average cost of residential services at privately-operated group homes, not to mention the cost to provide residential supports in the community. At the same time, nearly 1,000 individuals, most living in their family home, in critical need of residential services and supports --identified by DDS as "emergencies" or "priority 1" --go without services due to lack of funds. So I support the requirement for the Commissioner to develop a plan to deliver residential services to all individuals needing those services.

When it comes to residential services, a hallmark of the plan must be that services will be delivered in a more cost effective manner than the current system. Residents at Southbury Training School are gradually being moved into more inclusive settings in the community, and eventually the school, as well as the remaining 5 Regional Centers, will and should be closed. The services received by individuals who move from Southbury into the community will be different from the model of institutional care--a better and most assuredly a less expensive model. The closing of state institutions will likely result in job dislocation--we are being dishonest if we do not acknowledge that fact.

That is why I take a cautionary view of the final section of the bill. I would not want the language in that section--prohibiting the reduction of "other services" provided by DDS, and prohibiting the reduction of pay or benefits--to be interpreted as a restriction on closing the antiquated, expensive state institutions. The closing of those institutions will not only provide a more appropriate model of care and community living for the residents, but it will do so at a lower cost, making those dollars saved available to provide services for many other people with intellectual disabilities.

So I urge you, let the plan be developed with only one unrestricted goal, a full and fair assessment of the needs of individuals with intellectual disabilities and the cost to provide such services.

Thank you for the opportunity to testify on this bill.